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RE: SB414, 415, and 981

**Main points:**

- ~ A little bit about me...
- ~ There are issues, therapy is the answer...
- ~ We need more than what the schools can offer...
- ~ Simple Math

**A little bit about me...**

My name is Kate. I am a stay at home mother of two children that have been diagnosed with Autism Spectrum Disorder. My four year old son, Ryan, has moderate, low functioning Autism. My two year old daughter, Elizabeth, has mild, low functioning Autism.

I think why I am here is because over the last couple of years, I have met and talked with so many different families that are in the same situation as myself. So, I am here for all the families that I love and support.

**There are issues, therapy is the answer...**

I briefly want to give some examples of issues that parents face to show that these therapies are needed. I will keep this extremely short, but, would like to point out that there are thousands of GOOD reasons for therapy.

**Example number one: Communication**

My children use and understand language in a literal manner. Everything that comes out of my mouth must be short, sweet, to the point. If that doesn't work, I have to use different words, less words, eliminate background noise (such as turning off the radio or tv), sign language, pictures, iPad, etc. That is, of course, if I can get their attention and keep their focus long enough to get them to do what I need them to do. Pictures, social stories and picture schedules are helpful.

Communication is everything in the real world. Being able to ask for help when needed, especially in regards to safety. Occupational therapist can help with writing, in particular a functional grip with a pen or pencil. For us, we had to solve some sensory issues before the language really started to come out of my son. A speech therapist works on language and language comprehension. An ABA therapist can work on shortening the processing time of communication and cognitive skills.

**Example number two: Sensory**

We have had to go through all of the toys to make sure we do not have toys that over stimulate our children, or at least limit their time with them. With over stimulation my children do not focus, eat, sleep, etc. Over stimulation can be one cause of a meltdown.

A meltdown is a physical release of anxiety, it could be that there is too much sensory input for their brain to handle, and is not in any way, shape or form of manipulative behavior. The majority of the time I have to play detective to figure out what went wrong. When a meltdown happens they can become physical (such as biting, kicking, screaming, etc), but they are lost for words to express their emotions in a healthy way. This does not last for a few minutes, this lasts for hours on end. It can be over something very simple. What we can do right now is: use dim, indirect lighting, soft colors on the walls, bedrooms only have beds and clothing- not only for safety, but for a place where they can go to defuse from stress and picture/picture schedules.

All of these issues, with time, can be solved with therapy. Occupational therapists can help solve the sensory issues. The speech therapist can help with giving children the language to express what they are feeling in an appropriate way. The ABA therapists help fill in the gaps in their skills for them to lessen the anxiety in the first place.

I really want to put into words the success that we had, but, all I can say really is that we gained SO much from all three therapies working together in the three months that we were able to afford to do so. Early intervention and all three therapies working together is the key to success. Our success was HUGE. From shorting the processing time and gaining comprehension of language... to putting on our socks in a few minutes rather than one sock in a few hours. To being able to zip and un-zip his jacket and pants. He learned what emotions: happy and sad are. To being able to withstand being in the same room with another peer(s). We went from two word scripted phrases to five to seven word [almost] sentences- even some were spontaneous language that we haven't seen before. In a short amount of time, these were big accomplishments for us.

**We need more than what the schools can offer..**

The mission of schools is education, and education alone. I think that that is what the advantage of "outside services" are. Autism touches every aspect of life- communication, to self-care, so on so forth... The results of outside services lessen the need for special education services within the schools, thus lowering the overall cost for the school. Plain and simple, the schools cannot and should not have all of the responsibility of Autism needs. In fact, it is impossible for the schools to do so.

It is a hard pill for parents like myself to swallow that the school is only concerned about educationally based things. For example, the school OT is only concerned about holding a pencil to be functional enough to write and cutting with scissors. They are not concerned with self-care or sensory issues. For example, my kids have issues with cutting their finger nails and washing their hair. It sends a fight or flight signal through out their bodies, and seems more like a pain. Should we expect the schools to be

concerned with this? No. It is silly to think that they would be. They have their own list of goals to be completed by the end of the year.

There is the issue of potty training, some families and their children at the age of six or older, not being fully potty trained. My son is four and half and no where near ready to potty train. He has a hard time expressing his feelings of what his body is doing, such as the urge to go. His limited vocabulary or maybe it is simply he gets so focused on what he is doing that he ignores his body signals. Should the schools have goals towards potty training? Again, no, that is not the objective or mission of the schools.

Once again, there are too many aspects of Autism that the school was simply not designed or missioned to do. This is a BIG reason why we need outside services and why we need the bills to pass.

### **Simple Math...**

To simply put the problem: TRUE COST of having a child(ren) with Autism:

For one month roughly:

full-time ABA \$6,000.00

Speech and OT \$1,000.00

Multiply that by TWO because I have two kids: \$14,000.00...

Now.. multiply that by 12 months and that is... \$168,000.00. What comes to mind when you hear 168 thousand dollars? A starter home? People generally take out 30 year loans for those kinds of things, but Autism is not a one year deal. Its not even a five year deal, or even a ten year deal. This is a life time deal. These kids are always going to need some kind of help or support. The more we throw at them as children, the less we will have to pay later.

Even if we were to go to the bare minimum of ABA therapy, speech, and OT, that is still (roughly) \$77,000 dollars per year. For those families out there that just have one kid that would be anywhere roughly from \$38,000 to \$84,000 a year. Think about the families that have more than two children with Autism and what that would cost.

My family is considered low income, add a little bit more for SSI and the Michigan family support subsidy. Obviously, we don't even come close to having enough to have all of the therapy that is necessary. We pay close to \$70 dollars a week to have my husbands insurance through his work that doesn't cover what we need to cover. I would give anything to give my children ALL the therapy that they need without taking out loans or borrowing money. Even if I did to go back to work, we still would not have enough to live comfortably and pay for all the therapy needed. That is why is it imperative that we pass these bills because it IS that simple that the vast majority of these families cannot afford therapy.

**In closing:**

As a parent, it is our hope that we are able to have our children live successfully on their own, have a job that they love, have people in their lives that will love and care for them and vice-versa, and for them to be the best that they can possibly be. We have a need for therapy. We have a need for therapy that is beyond what the school can offer. Bottom line is, the vast majority cannot afford to do so.

I leave you with this thought, however... These kids will physically grow up. Whether we do something or not, I will say it one more time, these kids will physically grow up. We have to do better than what is available right now. We have no choice, but to do better than this... because after all... they are our future...

**Thank you for your time.**